



INFORMATION ON OSTEOGENESIS IMPERFECTA FOR SECONDARY SCHOOLS

Starting Secondary School

The transition from primary into secondary school needs to be planned and well managed. It is advisable to arrange a meeting, well in advance of the pupil changing school so that the key people involved in the pupil's education can meet him/her and parents, and vice versa. This gives everybody the opportunity to get to know each other, highlight specific needs that the pupil has and plan how these needs are going to be met. If the pupil with OI is a wheelchair user, the environment should be assessed to ensure that the school is accessible. Often an Occupational Therapist can assist in this area.

Dependant on an individual child's needs, it may be advisable at this initial meeting to develop a management plan specific to your school, which should include:

- ◆ **School Entry Plan / Care Plan / Fracture Management Plan:** The plan will describe the pupil's needs and how the school plans to meet these needs. The plan must also detail procedures to be followed if an emergency arises. Procedures need to be agreed between the parent and the school, following consultation with the relevant medical practitioners. Plans should be reviewed annually or if the pupil's health needs change. The plan should identify the key people and their roles in the event of an emergency. For more information please refer to the Brittle Bone Society Fracture Management Guidelines.
- ◆ **Risk Assessment:** It is the school's responsibility to carry out a risk assessment prior to the pupil starting school. This should detail all potential risks within the school environment and could be reviewed on a termly basis. Additional risk assessments will need to be carried out for school trips / activity days, special events or a specific manual handling risk assessment following a fracture. The OI team at the hospital may be able to offer general advice if required.
- ◆ **Educational Health Care Plan:** The pupil may have had additional support within their primary school setting. Often this additional support may have been necessary for break times / lunch times and physical activity sessions. This is very individual and specific to the pupil and is most often related to their physical, medical and safety needs as opposed to learning needs. These support needs may continue into secondary school and will require reviewing on a regular basis.

Learning Considerations

Absence: Due to the nature of the condition, the pupil with OI will likely have planned periods of absence from school for essential medical appointments and administration of medication. For planned absences it would be best practice to ensure that relevant work that will be missed during this time is given to the pupil / family so they have the opportunity to continue with their school work.

OI can also be unpredictable in its nature, the pupil may also have unplanned absences from school due to a new injury / fracture. This may or may not require medical intervention. If this is the case then close communication with the family should be maintained and essential work should be provided for them to continue with at home / hospital to ensure there are no gaps in knowledge. Return to school as soon as possible after any absence event should be planned. In exceptional circumstances of prolonged absence, home schooling should be sought as soon as possible.

Hearing Loss: Hearing loss is a medical complication of OI which can occur at any age and in pupils with any type of OI. This could affect interaction with the classroom / school environment, behaviour and ability to learn. If you have any concerns with regards to this it is worth in the first instance raising it with parents / carers.

Personal, Social and Health Education: OI impacts a pupil's health, and it can affect self-esteem, self-confidence, friendships and participation. Pupils with OI have the same needs as others to develop a healthy self-image and to understand their personal strengths, abilities, limitations and weaknesses. Secondary school plays an important role in the development of these skills especially as they progress into their teenage years. As with any pupil, teachers need to be vigilant about the potential for bullying and the risk of the pupil with OI being excluded from peer directed activities. (Please refer to the emotional wellbeing leaflet for more information).

School Environment

Consideration needs to be given to the current physical abilities of the pupil, but also the potential that they have for fractures. They may therefore have periods of time in plaster and may require the use of a walking aid or wheelchair, during which time they may require more support / space than usual. If a student is having difficulty with mobility they may require access to a lift for safety and to conserve energy.

Toilet and Changing Room Areas

A level access disabled toilet and sink will be required if the pupil is a wheelchair user. It may also be necessary to have specially adapted equipment /grab rails / small step to facilitate safe and independent toilet transfers and hand washing for more mobile pupils. Changing rooms with shower facilities within them may have wet floors, increasing the risk of slips. Caution should be taken in these environments to minimise these risks.

Lockers / Corridors

Lockers (if able to be provided) should be at a height accessible to the pupil and preferably at the end to prevent the pupil being pushed / knocked during busy periods. It can be advisable to have an early / late arrival / exit to and from the classroom to allow for safer travel in the corridors, and often it is nice if a friend can accompany them so they don't feel so isolated.

If lockers are not available then it is sensible to allow the pupil to leave heavy books within the classroom to minimise the amount they have to carry.

Tables and Chairs

Often pupils with OI are much smaller than their peers, and may therefore have some form of specialist seating for use in the classroom. Other times more simple measures may have been provided/ recommended. Usually an Occupational Therapist or a Physiotherapist will have been involved in this process and should be able to advise further. If the pupil is in a wheelchair then the table needs to be accessible for them and at a good working height.

Physical Education

Guidance should be sought from the Physiotherapist involved with the pupil when planning their PE lessons. Please refer to the 'Including Pupils with OI in PE' leaflet for further information.

Science and Technology

Seating for these lessons is usually a stool, more commonly with no back. Sometimes it may be necessary to consider an alternative option. Other difficulties may arise when using equipment within these lessons. If this is a concern then please seek the advice of the Occupational Therapist involved with the pupil.

Fine motor skills / Handwriting

Pupils with OI may have upper limb deformity resulting from fractures, although hypermobility (joint laxity) is often the main problem. This can affect grip, power, stamina and may therefore cause problems with handwriting. Provision of a laptop for longer pieces of work, extra time in exams or provision of a scribe may need to be considered. If you are concerned about this an Occupational Therapist can often complete a more formal assessment and make recommendations for you to try.

Tiredness, aches and pains

Due to bone deformities, bone pain and / or joint hypermobility, pupils with OI do experience a great deal of pain and can tire much quicker than other pupils of a similar age, especially following physical activity. Discussing the management of this should be in conjunction with the pupil, parent and school nurse as at times medication may be required. If your child is on medication discuss this with the school.

Break times / Lunchtimes

Pupils with OI tend to eat more slowly and can sometimes have problems with their teeth and therefore you may notice that they take longer to eat their lunch. It is advisable for the pupil to enter the dining hall at less busy periods to avoid any unnecessary collisions / bumps.

Transport

It is not appropriate to expect a pupil with OI to get on a busy school bus unless they have a guaranteed space on the lower floor with a friend. Families often help by transporting to and from school, but when that is not possible, appropriate school transport should be considered. This is particularly for the more severely affected students, or following a fracture.

School Outings

A pupil who can normally manage short distance walking within the school environment may not manage as well on a trip that involves moderate walking or activities. If so the pupil may require more regular breaks and / or the use of a wheelchair during these times.

Plan with parents in advance of these trips and do a risk assessment.

Careers Advice / Work Experience

This should be appropriate to the pupil's interests as well as their physical capabilities. If they need support at school it is likely that they will need this for work experience. It is important that any equipment needs are identified and addressed prior to starting the work experience placement. The Therapists involved with the pupil will be able to support you further with this.

General Advice

- ◆ Physical and psychological wellbeing should be considered at all times.
- ◆ If the pupil is receiving Bisphosphonate treatment for their OI they may tire / be in pain towards the end of each treatment schedule (for further information on this please refer to the Bisphosphonate treatment leaflet).
- ◆ Although a pupil with OI may be restricted in some activities, they should still be included in all aspects of their education and school life.

Compiled by the Brittle Bone Society in collaboration with the Paediatric Osteogenesis Imperfecta National Team (POINT) - special thanks go to the Metabolic Bone Teams at Birmingham Children's Hospital, Bristol Royal Hospital for Children, Great Ormond Street Hospital, Sheffield Children's Hospital and Royal Hospital for Children, Glasgow.

The information in this leaflet is correct as at 31st January 2020 but we cannot guarantee that it will be accurate and current at any given time. This leaflet is not intended in any way to replace the advice of your doctor or other medical professional. Leaflets are available online at www.brittlebone.org. This information is available in accessible formats on request.



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*Working with People
who live with
Osteogenesis Imperfecta.*